

A. R.

## Dingdong Manifesto

*Translated from the French by Damien Bright*

“Don’t look at what you’re losing,  
look on what you’ve gained.”

My mother

In the beginning, when the world was just fifty centimeters long, there was Jeanne’s inquiring face. A five year-old face, flush up against the months-old fragment I then was, my opaque little mole eyes fumbling across this earliest of landscapes, my sister’s face watching me. She smiles, I smile. I smile, she smiles. She gives me a quick slap, I cry, she smiles, I smile, she gives me another quick slap, I cry, she smiles, I smile. Late at night, we bond. My father bursts in, he sees me in my crib, he sees Jeanne as she leans over me and gives me a quick slap, he sees me cry, he slaps her, she cries, I cry, we cry, he gets angry. He doesn’t understand. Jealousy, hostility, who knows what he assumes, but he thinks: here’s a problem that needs fixing, separate them.

In the beginning and evermore, the limits of the earth, its firmament, its floor and its ceiling, they’re Violette, who tackles everything with an eight year head start, in other words an entire lifetime. Violette has a whole life on me, she goes on ahead, far in front, as big as the sky. She’s scatters her protective pheromones around me, something quakes in her when it quakes in me, our connection draws on resonance, and whether she’s here or not, it’s a thing of taut threads and a stiff winds that carry fast and far. Early on, thanks to her, I learn that unconditional love does exist. At the same time, thanks to her, I learn that all love is not equal and that rare is love so verily unconditional. I can act out, I can be away for years on end, I can fling myself every which way: she’ll check if I’m still alive, sometimes gently reproach how I am mistreating myself, and then lets me go,

loving me as always, which is to say without the slightest qualification, unequivocally.

There you have it. Nuzzled against me, one builds my self-awareness and the other that of the world around me, danger/no danger. (For a long time I thought none of this was mutual. I thought that for them we were just three sisters, and that I was the only one who saw it differently: the three-of-us.) My existence is stitched in double lining. And if I've forever sought to break these seams, to pierce them, to blaze my way through them, it's because wherever I go they will always keep me together. When we learned that our mother had Huntington's disease, I hurried. I'm like that, I hurry, I rush things, I tear along, I rough draft, because all of my trials and errors are padded by my sisters, my double lining. It's not about rebelling, or getting defensive about overprotective care, just the opposite: my sisters exist and so doing protect me, and so I am blessed with an incredible gift, the power-cum-duty to take risks. When my test results for Huntington's hit the red, they both jumped. When I'd rush into things, it often made them skittish, but this time they really jumped. I looked at them tremble with fear, body and soul, and my self-centered understanding of things finally came around to the fact that the three-of-us share a highly sensitive reciprocity mechanism: my sisters' lives also depend on mine. As we made our way in life through our respective bouts of trial and error, I had not concerned myself with this existential reciprocity, but ever since we learned that it was yes for me, no for Violette, and maybe yes maybe not for Jeanne, the world has really begun to shake: the problem is not that I'm struck, rather that the three-of-us are. Anything can happen to me on my own, indeed must happen to me on my own, because that way nothing happens that the three-of-us cannot deal with. But if something does happen to the three-of-us, there's a real danger it will all irreversibly unravel. That's why now I'm going to start at the end. It doesn't matter how the three-of-us came to be. It doesn't matter for now how many millions of minutes make up this singular thing, the three-of-us. The only thing that matters now is the emergency of dealing with what Huntington's has threatened to pollute in one fell swoop.

We were stunned, when Violette's test results came back negative three months after mine, by how devastated we both were, right when we expected we'd be jumping for joy. Violette's results were a good thing and they vindicated my conviction, steadfast from the very outset: Violette is to be spared from this bullshit. Violette, my

compass, my very big sister, my little mother, founder of her very own clan that has since also become mine given how the three-of-us constantly entangle ourselves: spared from this bullshit, one and all. At almost that same exact moment, however, I was enveloped in a sphere of pure loneliness, a white and silent nucleus, that abrupt and radical removal from the world. (Maybe when someone drowns, there's a point where they encounter this same loneliness and at that moment they know that nothing is more real, more true, the slightest idea, the slightest concept is annihilated by the absolute purity of this loneliness.) I did not expect I would react by developing such an injury, such an open wound. With one blow, more than ever before, Huntington's had polluted me. It was not my test results but Violette's that led me to understand what was really going on, only then did the three-of-us pollution become clear: no for her, yes for me, and a tragic yes or an equally tragic no for Jeanne regardless. Hence what I'm now fixing to imagine, a reaction in phase with the three-of-us. It's like the word game we so loved when we were kids, where you aren't allowed to give a yes/no answer. It's not the path of resistance, but of of imagination. A merely defiant response will not overcome Huntington's pollution of the three-of-us. If we managed to invent the three-of-us, we can find something better than a yes/no answer for Huntintgon's.

Huntington's. The three-of-us learned that our mother had it first, which was difficult because she didn't know that we knew. Many years ago, when her father told her he was sick, he gave her an article on the subject from a medical journal, she tucked herself in a corner and read it alone, didn't tell anyone anything, and then ended up going for the blood test. Huntington's is an autosomal dominant disease, which means that if one of your parents is affected you've got a fifty-fifty chance of contracting it too, making you an "at-risk" person for the medical system. Since the genetic mutation was identified in 1993, to date it is the only neurodegenerative disease with a predictive test for at-risk persons. Technically, nothing could be simpler: you just take a blood test to find out if you have the bad version of the gene or not. Philosophically, ethically, psychologically, existentially, nothing could be more difficult, for Huntington's is a completely penetrant monogenetic condition: knowing you carry the abnormal gene means knowing with absolute certainty that one day you will develop the disease, yet not knowing whether that will be in three, five, ten, fifteen, or, if you're lucky, twenty years. My mother had the blood test done and then waited two years to go get the results. That was ten years ago,

she learned she had the abnormal gene, then the disease, the very same condition that was incapacitating her own father, and throughout all this she did not tell a soul, especially not us. For ten years she did not say a thing. It's incredibly difficult to fathom: my mother's loneliness, my mother dealing with it all on her own, all this time. I cannot imagine it. And when I try to anyway, I'm overcome with tears of compassion: my thoughts stop and my head fills with terrible anguish for her instead. Much later, when we asked her why she kept it from us that whole time, she answered that she simply wanted to protect us. "Telling you such a thing when you were barely twenty years-old, you must be mad! Why would I do such a thing?" She wanted to spare our twenty-somethings. To tell us or not to tell us: it was an impossible dilemma for her, and so we had to guess instead. And, after seeing her decline mentally and physically over so many years, without understanding what was happening to her, that's just what we did.

When the truth eventually came out, when we learned that Huntington's ran in the family and that our mother was sick, I already had a bit of an idea what to expect because of my training in psychology. I had hated that train-wreck of a class:

multiplesclerosisalzheimersparkinsonshuntingtons

Truth be told, it was more of a course on disability than anything else. Neurodegenerative diseases lead to the following physical disabilities and mental disorders, blah blah blah, there's nothing you can do about it, in fact nobody can do anything about it, so the best thing you future carers can do is work with the disabled patient through mourning her normality. She's descending further and further into abnormality but she doesn't know it so you've got to help her recognize what's happening, in other words what she no longer has, or maybe she knows but won't accept it, and then you've got to help her mourn this loss. I had to write up all of this in my notes, and then recite it all on exam day to get a passing grade. I remember coming up with an exorcism ritual to cleanse myself of this foul nonsense straight afterwards. The classes taught us to transform people into anybodies<sup>1</sup> (*quiconque*), it wasn't a course in psychology but a course in anybodification (*quiconquisition*), and at that time I already found it

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<sup>1</sup> Tobie Nathan, "En psychothérapie: maladies, patients, sujets, clients ou usagers?" Conference given on October 12<sup>th</sup>, 2006 at the colloquium *La psychothérapie à l'épreuve de ses usagers*.  
[www.ethnopsychiatrie.net](http://www.ethnopsychiatrie.net)

infuriating. Two years later when I crossed over to the other side, however, when I myself became a subject of medical anybodification, it did not matter that I was angry, it did not matter that I had worked “in the field” and had already given considerable thought to the matter – on certain medical practices’ knack for capturing and purging, for instance – none of this protected me from the medical machine’s remarkable power to anybodify me. Not one bit.

When we find out about her illness, all of a sudden my sisters and I have to revisit the last fifteen years of our mother’s life, the last fifteen years of our own lives, the last fifteen years of our relationship with her. With this news, much of her odd behavior can be understood very differently. At the same time we are flung up against our own futures, now instantly and forever changed: Huntington’s runs in the family, and each of us might have it, a fifty-fucking-fifty chance. At the time, the three-of-us are often overcome by waves of turmoil, by fits of anger, but rarely in unison. One of us whips into a rage, another slips into a Zen-like calm, the third falls somewhere in between, and the roles change from one moment to the next. That’s still how it is for my sisters and me, we each dance a solo, taking turns, and we very rarely perform as a trio. One goes off and explores the hostile extremes while the others stay back and guard the base. When I learn of my mother’s illness, I talk a lot, get tired, every day I think my understanding is getting better, stronger, deeper, but sometimes I trip and fall flat on my face, from really high up, and then all the meaning, all the meaning built up all that time flushes down the drain. Sometimes all that work makes my stomach weak, like having indigestion. I get a little quieter than usual then, I get stuck on repeat: I don’t know, I don’t understand. I forget how to start the thought process up again.

At this point, we don’t talk about it with our parents. Our father is undergoing cancer treatment and our mother doesn’t yet know that we’re aware of what she’s been going through. And we don’t know how to go about telling her. My eldest sister and I go to see a shrink at a neurology clinic specializing in Huntington’s hoping to better inform ourselves and get some advice on how to act towards our mother: how do we tell her that we know? Is she aware of her symptoms? What should we do to not upset her? The psychologist, who has never met our mother, her white lab coat doing all the talking, tells us that our mother is mad anyway and doesn’t realize what’s happening to her. “No matter how you go about things with her, it

won't make a difference because she's anosognosic." This sinister word is the lecherous starting point for any attempt at defining Huntington's. It means that the patient is unaware of the horrific psychiatric and physical symptoms caused by the disease. The psychologist tells us our mother is anosognosic with a smile dripping with the magnanimous sputum of closure: what I'm about to tell you is how it is, and it's *for your own* good, you'll have to get used to it. Regarding our own peril, she suggests we think of a coin: it's just a matter of heads or tails. We leave her office more dazed than ever. I find somewhere to hole up, far away, I need to be alone. I don't do anything except bury myself in Rachmaninoff, in his language of war, for two weeks, I turn myself inside and out, and end up deciding to get tested. All in all, I'd spent six weeks thinking about it. First I wanted to get tested, then I didn't, and in the end I decided I wanted to know. We weren't designed to know our destiny before it happens, says one expert. I agree, but when you have got the option to know *anyway*, it automatically alters you somewhat, as a human being. I wanted to know so as to not be sick. To rid myself of medicine and disease. I was convinced I was not a carrier, I wasn't shouting it from the rooftops, but I was both terrified and confident: I don't have this thing. If I had it, I'd have felt it, I would feel it. Feel what exactly, I didn't rightly know. But I also knew that if I didn't get tested I would be wracked with doubt, like a house haunted by a troublesome poltergeist that wreaks havoc day and night.

Jeanne is less frightened than Violette and me at this time, she didn't go with us to see that hospital shrink, she isn't corrupted, her connection to it all is much simpler and more candid, and so one fine day, without any warning whatsoever, she turns to our mother, uncorks a bottle of champagne (because for us champagne and announcements go hand in hand) and tells her we know that she is sick. She brings her up to speed and everyone cries, not so much with sadness as out of tenderness: we have found each other again, after all these years of senseless separation, we are together once more. My mother is immediately overwhelmed with relief at no longer having to live alone with this knowledge, because she blamed herself terribly for not saying anything yet would have blamed herself even more had she told us, for it would inevitably have poisoned our lives – our lives, that which she holds most dear. Our mother's reaction is the exact opposite to what the specialist shrink had predicted. She is entirely aware of what is happening to her, she is not the slightest bit mad and can understand everything we tell her as long as we communicate

things clearly for her. This is one of the first lessons we learn: to see someone as anosognosic – as the psychologist had encouraged we look on our mother – sows confusion, misunderstanding, and estrangement (we're normal, they're abnormal). It places this person in a world that isn't quite ours anymore, the very world of anosognosia. The belief that Huntington's and anosognosia go hand in hand, and the associated impact on how you behave towards those affected, causes as much anosognosia as the condition itself. In this cruel mystery, came to regard anosognosia with the greatest of suspicion.

I set off on the path to genetic testing. I am told it will take time: three months, maybe more. First I meet with a neurogeneticist, who explains that I have to see a psychiatrist, a psychologist, a social worker and then another geneticist before getting the blood test done. I manage to get around the social worker and the psychiatrist. I meet with a psychologist who asks me why I have decided to get tested. I explain everything candidly, and her response is that I appear quite unemotional, that I should let my feelings out. What about a slap in the face, how's that for feeling? Or maybe she had rather watch my emotions and I yank the drawers from her desk and roll around on the floor sniveling and in tears? The other geneticist is an old man who scrawls impenetrable diagrams full of arrows on bits of paper while he talks. I leave with his scribbles, more confused than ever about what they are all going on about. Meanwhile, I Google Huntington's disease six ways from Sunday and become more and more terrified at what I find. Soon enough, I stop being able to type the words "Huntington's disease" in Google's search bar without literally starting to shake. My investigations grind to a halt. I have to go back and see the first neurogeneticist again, to let her know whether I've decided to go ahead with the blood test or not. It feels like a driver's test: I have to prove who I am, they have to think I'm strong enough to quell their fears that I'll kill myself because of them, yet I also have to appear upset enough not to come across as emotionally shut down. It's a tricky line to walk, but I end up pulling it off and they allow me to get my results two months after the start of the testing process, the hallmark of a successful applicant. They draw two vials of blood, because the results have to be double-checked by two different labs.

In the weeks leading up to the test results, the more the night draws on, the less tired I become. Lying in bed, my mind wanders, eyes wide open in the darkness, and I go looking for this hypothetical foreign

body that, unbeknownst to me, might have been living within me this whole time. Huntington's disease. I don't find or feel anything in particular except for the sheer terror of the expedition itself. Often I have strange bodily sensations, I experience astonishing ways of thinking and feeling, tingling, electric shocks, dissociations, murderous thoughts, a lot of desire. My thoughts jump seamlessly from one subject to the next, or the exact opposite occurs, they come to a complete standstill, like the ceiling above me, I experience all of these things, yet remain aware enough throughout to know that for the most part these phenomena stem from that same question – "have I got this thing in me?" – and were not always there, making my body their home sweet home. That very question sets off this rollicking jig of physical sensations and sudden, strange thought processes, not so much moments of weakness as moments of panic where my brain works at lightning speed to find an answer. Soon enough I'm barely sleeping or eating, all I can do is think, and I don't want to do anything else. Hours seem to go by like seconds while I investigate the possibility of this occult marriage, Huntington's and I. I now know that the question of whether or not I was a genetic carrier was not alive. In the words of William James, the hypothesis I could be a genetic carrier was a dead hypothesis because it did not appeal to me "as a real possibility".<sup>2</sup> The question was a zombie question, and I was its prey. It produced no vitality whatsoever, and was maybe even dead itself, but when this question captured me as it did, I was wholly and utterly at its command. With the test results a few days away, having looked long and hard and found nothing much at all aside from the side effects of the question itself, I latched onto the certainty that I was not sick.

On the day itself, I went to see the neurogeneticist for a third time. Emmanuelle came along with me. She had been by my side every step of the way, playing my girlfriend at each appointment (given they asked me to play a part, why not take it all the way and pretend to be homosexual?). Another close friend also came along, and it is fortunate they were there because I have no recollection whatsoever of

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<sup>2</sup> "Let us give the name of hypothesis to anything that may be proposed to our belief; and just as the electricians speak of live and dead wires, let us speak of any hypothesis as either live or dead. A live hypothesis is one which appeals as a real possibility to him to whom it is proposed. If I ask you to believe in the Mahdi, the notion makes no electric connection with your nature,--it refuses to scintillate with any credibility at all. As an hypothesis it is completely dead. To an Arab, however (even if he be not one of the Mahdi's followers), the hypothesis is among the mind's possibilities: it is alive. This shows that deadness and liveness in an hypothesis are not intrinsic properties, but relations to the individual thinker." James, W. "The will to believe" in *The New World*, Volume 5 (1896): [pp. 327-347](#).



the moment when my test results were revealed. My memory refused to capture it, and my two friends now carry the memory of this instant for me. I can only remember the neurologist telling me it was bad news, and that she herself was surprised because, she said, more often than not in her experience she did not need test results to recognize, know, or sense that someone had the disease. And that she hadn't "seen" any such signs in me. She delivers the sentence as my CAG number: 44.<sup>3</sup> No need for a second opinion. The number is well above the threshold that separates those carrying the disease from those who do not. She then turns to Emmanuelle and tells her how difficult it is for family and friends, and that she needs to quickly start getting help herself. Not content with cursing me, she dunks my friends in her pox as well. All I can think about is fleeing this place as quickly as I can, but first I have to listen to her advice about coming back to see them and undergoing treatment with their team of shrinks. I make a silent oath never to see her again. I close my ears and manage not to break down (my emotions and feelings are chunks of intimacy that she does not deserve). Outside in the corridor, five minutes later, I collapse for a moment. I wait until I've left the hospital to scream.

Throughout this entire journey, I never felt as if anything other than a predetermined set of reactions and behavior was expected of me: "good behavior", the kind that would grant me what I wanted, to take the test. Taking the test – because from the moment it existed, from the very moment it had been created, I had to take it. The simple fact the test existed made it utterly irresistible to me. When I learned of my mother's illness, all my bearings past and future skipped town and the test revealed itself to me, quintessentially, radiating with the glory of its absolute certainty. Because there was a test, I could not do without it when erecting even the slightest of solid foundations for my future. Every hypothetical construction of self I would devise independently of the test was necessarily based on hope, on a "maybe not", one step removed from the denial of reality that we psychology practitioners so gleefully condemn.

Devising such an instrument, the predictive test for Huntington's disease, such a resolutely vertiginous instrument, and then allowing it to become the withering process I underwent, is I believe not only a

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<sup>3</sup> CAG stands for Cytosine-Adenine-Guanine. More than 36 repetitions of this glutamine on the 4<sup>th</sup> chromosome indicate the presence of the gene responsible for Huntington's disease.

deep disappointment but the sign of a very grave, unforgivable failing of medicine. The test is a destiny-making machine. Going through with it means witnessing the radical and immediate transformation of your inner truth, that constantly quivering kaleidoscope, into the simple truth of a medical definition. My kaleidoscope and medical definition do not share the same modes of existence. I am willing to incorporate a medical definition into my kaleidoscope, but medical definition is not able to integrate my kaleidoscope without destroying it down to the last shard. In the case of Huntington's the test had transformed medicine into the very provider of singular forms of truth, truth-which-cannot-lie, the specificity of which is to crush all others before it. As the testing process wore on, the geneticist kept saying that if the outcome were bad, what she'd have to tell me would not be a diagnosis (of my current state) but information (about my future state). Yet when it comes to a genetic condition like Huntington's, where the genetic anomaly is completely penetrant, the distinction between information and diagnosis is far too subtle to be of any use. The test is formidable. I do not regret having taken it, because there's no point regretting the inevitable. However I do regret that it was invented. Had it not been invented, I would not have taken it, and I would have had to construct something else from the news that my mother was sick. I realize today that I had two possible destinies: not "with or without Huntington's", rather "with or without the test".

Experts carefully argue that the test is not so much a matter of diagnosing as "revealing genetic status". Sure, why not! But in that case why stop there? They should work with us on this new enigma of theirs: what does it mean for a person to have their genetic status revealed? There's nothing trivial about a revelation, it's a big deal, and I agree with geneticists when they talk about revelation to describe the predictive test – but I do not agree with the conclusions they draw from such an experience. Revelation does not inform you, quite the contrary: it transforms you. It can either make you sick or make you better: it all depends on what you do with it. As for me, and I know I'm not alone on this one, the test stopped being a curse from the moment I separated and protected myself from medicine.

I blame the scientists and doctors for making an offer that was too good to resist for someone in my position<sup>4</sup>, and then to display such

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<sup>4</sup> Early thirties, single and without children. The decision to get tested or not is intrinsically linked to your personality, age, relationship status and whether or not you have children, in which case

galling incompetence, not so much towards me as towards their own creation, the test. The process itself reflects this problem every step of the way. The doctors I met with were both terrified and fascinated by what they were having me do. And from this strange vantage point, the best they could offer me was depressing and corrosive stereotyping. The only pronouncements they made were condemnations: your mother is insane, your life is a coin toss, a matter of heads or tails, it's going to be so difficult for friends and family, there's no treatment, you are very healthy for now but when you get worse you will come and work on your disability with us, what's that – you plan on adopting a child?!... [expression of horror/sympathy]. Thinking through Huntington's disease together, thinking through this terribly enigmatic business, was just never an option for them. Perhaps they aren't there for that because they are doctors and not philosophers. Perhaps they are just there to treat you and make you better. The problem with Huntington's however, is that there is no making you better: the disease has no cure.

Here's exactly what I blame them for: not that they can't do anything to help (they're not omnipotent, I realize that), rather that they opt for a default professional viewpoint bereft of humility and cowardly to boot. If you don't have the technical means to make me better, yet you have got a hold of this test – an instrument too powerful for you to handle – try and take the opportunity to learn something, try and push yourselves a little: the situation is not business as usual so don't act as usual. Don't look at me like it's "been there, done that." You're telling me my future is Huntington's and then you say I'm not emotional enough? Do you realize what an absurd and destructive position that is? The problem is not Huntington's incurability: the problem is that the test holds you as you hold it. It demands that you be able to make something living out of it. But you wouldn't dare. You are cowards, your conscience is sitting pretty while we struggle through the test, and you take every opportunity to belittle us as we go.

Therein lies my anger. Those who get tested give you a chance to lift your standards, and you do not take it up, quite the opposite, you want to anybodyfy (*quiconquiser*) us as usual. And so doing, not only do you not fix us, you make matters worse. You make our situation even more depressing than it is, because you block off possible escape routes and flatten our futures. You concoct a Huntingtonian future for

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the curse inevitably takes hold of their futures. Thankfully these days, a vast majority of at-risk people decides not to undergo the testing process.

us that is bland, mediocre, handicapped, insane, predictable – a definition wrought by you alone – without thinking for one second that it might be possible to have Huntington’s and completely eschew the model you’ve created, by being doggedly out of step with your definition. It never occurs to you that you do not own us, that we could be something other than your creatures. And how could you? Your power to transform humans into medically conforming creatures, into beings defined from head to toe by you alone, this power is such that, once caught within its cogs, it becomes incredibly difficult if not impossible to disentangle and defend oneself. Most of the time, getting sick is a double bind: illness on the one hand, medicine on the other. Should a sick person begin to challenge her treatment, she soon finds herself in pain and alone. At best, her aggressive behaviour is explained away to her as the result of feeling that, as a sick person, she is the victim of some sort of injustice for which her anger can find no other outlet. At worst, say if she’s a smoker and happens to enjoy a drink from time to time, she is told that what is happening to her is her fault anyway. How do we dare to question those with the power to make us better? A power relationship such as this, which quashes and silences any semblance of a challenge, is profoundly unhealthy. I’m lucky: medicine cannot do anything to help me, which is why I’m free to criticize it.

My indignation is greater still when it comes to psychology’s attitude towards Huntington’s disease. If medicine considers that thought production is none of its business, so much the pity. For psychology to take a similar view is, however, astounding. As always, in the testing process for Huntington’s disease psychology intervenes when medicine hits a dead end. And when the moment comes for psychology to take up this glorious and ambitious charge, to generate healing in spite of it all, it too sets to work on its default setting, bathing me in preconceived and pitifully inadequate notions like “the grieving process”. Psychology too is determined to treat me like its been there and done that, and so doing serves medicine’s needs and not my own, applying its tools to reinforce the impact of the medical curse. Encouraging me to work on mourning my normality is not only stupid but also dangerous. I’m not dead yet. Maybe I shouldn’t have been born, but I’m not dead yet.<sup>5</sup> And like most of us, I was never normal. Telling me to grieve for my normality places me within a

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<sup>5</sup> These days women who carry the disease or the genetic expansion and who decide to conduct a prenatal test when pregnant, are advised to have an abortion if the results indicate the fetus is also a genetic carrier. Carrying the disease means being forced to live alongside this eugenic logic.

normative program of long-term, existential withdrawal that destroys all the singular possibilities contained within my experience of becoming-Huntington's before they've even been explored.

I understand medicine's difficulty as guardian of the genetic test, whether it likes it or not. The art of the test is in its hands, and yet it is ambivalent about making it available to the infamous "at-risk" population, particularly after having observed a rise in suicide attempts from individuals who test positive for the disease.<sup>6</sup> And if there's one thing medicine hates it is killing people: indeed its sole obsession is making sure that people do not die, or if they do that it is absolutely not medicine's fault. Medicine is right to fear suicide attempts from individuals who follow through with the predictive testing process. This risk is embedded within the test's very outcome. My hypothesis is that as things currently stand and in terms of their respective effects, the disease and the test are one and the same. The test deforms your life, whether you carry the disease or not. If it shows you not to be a carrier, you have nonetheless been possessed by the prospect such that, you are irrevocably transformed. Upon learning the good news, what do you make of this stunted metamorphosis? Not to mention the rift that such a result creates with those in your family who are sick. How do you rejoice without placing an irreparable distance between you and them, without feeling guilty? If the test says you are a carrier, your path in life takes a degenerative, downhill turn. Checkmate. The process can fuss over you all it likes, with its social workers, psychiatrists, and psychologists. It does nothing else but confirm and empower the shriveling malediction uttered by the test. Under such conditions, depression and suicide attempts are hardly unexpected. In fact, I'm surprised anyone survives the experience at all.

Through this powerful labeling process, where the only vanishing point provided by medicine is a generalized withdrawal – deterioration – it immediately occurred to me that suicide was the only alternative with enough power, counterpoint and emancipatory freedom. The thought seized me straight away: if I'm going to deteriorate, may as well finish it right now. I'm not interested in that future, I reject it and if, as it seems, I'm not able to reject it, if the only thing I'm offered is to help me accept it, then I'll stop all this right

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<sup>6</sup> Almqvist EW, Bloch M, Brinkman R, Craufurd D, Hayden MR, "A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington's disease". *The American Journal of Human Genetics*, May 1999, 64(5), 1293-1304.

now, because I'm not interested in accepting such a thing. I refuse to consider that life is deterioration. I have never, for instance, considered that ageing is an unrelenting phase of decline, that it is set to be that equation they drum into us: the older you get, the less you get. Less strength, less health, fewer memories, less sexuality, less flavor, less knowledge. I've never got my head around that kind of thinking and if, after all that, because of Huntington's, I'm forced to think of myself as someone who will never again be moving forward, well then too bad, I'll end it now one way or another. I began to think this way from the moment I was polluted by the medical definition of Huntington's and, more generally, by the medical definition of my genetic status. From this pollution onwards, committing suicide was therefore the only sensible answer to an absolutely senseless medical proposition.

I managed to rid myself of this pollution by quarantining away medicine, by realizing that what ails me is not so much Huntington's disease as a disease for which medicine has found a definition but can do precious little else. By understanding that medicine defines nothing, that you have to take its definition for what it is: a stop sign, beyond-this-point-we-are-no-longer-competent, in other words an object still needing to be thought through and defined. By understanding this, I began to breathe again. Medicine takes its own limitations as a working definition. The test creates Huntington's disease as an evanescent and all but hollow vessel, yet one that, like a ghost, is utterly possessive and terrifying. Each time a patient takes the test and is told of her Huntingtonian future, one of these disturbing creatures enters the world. The testing process and its design principles of precaution and anybodyfication, address this creature the only way they know how: domestication by way of notional deterioration. As such, the situation resembles a state of war. Medicine is my enemy for it insists on wanting to brand me with its moribund future. It can be my ally if, and only if, it agrees to fashion a surfeit of intelligence (i.e. vitality) from what's happening to me.

It took me two years to get better. Not from Huntington's disease, but from the psychological trauma I experienced when my test results were announced. I call them "tragic spells": they're just as powerful as magic spells but they make you rot, reducing the multiplicities of tomorrow into a narrow, monolithic, flat, *diagnosed sick* future that stops the mind from the business not of grieving but creativity.

I recovered because I met a specialist neurologist who agreed to embark upon creating an antidote with me. This doctor's patience and common sense are impervious to assault and her commitment and empathy is extraordinary. As I see it, however, these qualities are not what make her so effective. (Incidentally, I do not doubt that within the medical profession, of which I have been so vehemently critical here, many are those who possess these same qualities). I believe her ability to make this antidote stems from one thing only: her humility towards the disease, an a priori humility. She could have said no for the simple reason it's not her job, which is to treat the truly sick and not look after pre-symptomatic carriers sickened by the test like me. But she offered to do it, and most importantly she offered knowing full well that neither she nor I had any idea what we were getting ourselves in for. From the moment we were both of this mind, the antidote wasn't that hard to make. It consisted of a slow and gradual reinjection of everything that might have been eroded by the test: doubt, uncertainty, hesitation, the maybes, what-ifs, and feel-your-ways. In other words, she put her stock in pragmatism (following what this experience could teach us) rather than determinism (knowing in advance what would happen). Along the way, within the very core of this abstract, bland, and empty place called the genetic-coding-of-Miss-A.R.-with-Huntington's-mutation, she knitted, strand by strand, the possibility of releasing surprise anew, and displacement, disorientation, zigzagging, depth, perspective, insight, unknown knowledge – simply put, a dose of living-living.

In a few words, my task now is to invent a solution akin to a counterpoison in its nature and its action. To devote your entire being to devising a truly operational solution is an undoubtedly vitalizing path – so much so that I often wonder if life and the endeavor to create this solution are not one and the same. When it comes to developing this solution, anything that cannot be put to the test or into the world is of no interest. In this sense, my process is one of pragmatic research, drawing on the notion of a Jamesian wager.<sup>7</sup> For William James, when you're faced with a painful, stultifying and moribund existential conundrum it's time to have a wager, a somewhat therapeutic wager with a revitalizing thrust. James points out that once I've designed this

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<sup>7</sup> See the medicinal work of James, *W. op. cit.*

wager, I have to set about building up everything that will help me pull it off. It's like he's asking me not just to bet on a horse, but also and above all to make sure the horse wins, by taking care of it, readying it, by riding it and, who knows, why not even by becoming the winning creature myself.

Intelligence is the relationship that thought forges with reality, the world, and adjacent sources of intelligence. Intelligence cannot exist, cannot unleash itself, unless it is extended through contact, in an interactive mode. To emerge and develop, it must enter into an almost loving relationship with who and what it encounters. Here, I wish to suggest the conditions to ensure my solution is grounded not in the energies of despairing loneliness but rather collective emulation. Inventing an alternative understanding of Huntington's disease is an extraordinarily ambitious project needing robust means and a number of able minds to see it through. The greatest risk posed by such an experiment – having-Huntington's-disease – is that the illness becomes separated from its own intelligence, which would kill both things: a patient's intelligence, and the potential for intelligence inherent in the disease itself. My wager is that Huntington's disease provides an opportunity to push thinking further.

Dingdong was born to give me the means to win this wager. Dingdong is a collective whose sole vocation is to create a living and operational way of thinking through Huntington's. This collective does not intend to collate general information about the disease, or raise funds to treat those affected by it, which existing organizations do a remarkably good job of already.<sup>8</sup> It's not a federation but a gathering of individuals driven by a common, vital concern for creating innovative thinking from their experience with the disease. The collective's communication strategy could be termed *proffercation*: no condemnation without a counterproposal. It's not a collective *against* anything – against the disease, for instance – but rather *for* building something that does not as yet exist, above all a specifically Huntingtonian way of thinking whose current lack exacerbates the suffering of those affected by the disease.

Dingdong is first the call of three bells whose voices ring true and clear and yet who, like the three-of-us, are linked together, an echo of

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<sup>8</sup> In France, see for instance: Huntington France: <http://huntington.fr/wp/>; Huntington Avenir: <http://www.footconcert.fr/>; as well as the messaging boards for those affected by Huntington's such as <http://www.huntington-inforum.fr>, etc.



folly ringing in their heart. It's a warbling call, high and loud, to cut through the brouhaha of routine thoughts and warn of an urgent need to slow down. It's a call that chimes with Huntington's, so much so that for the three-of-us it became an acoustic compact: say Dingdingdong when you're too scared of Huntington's, and say Dingdingdong when you want to laugh or scare off Huntington's.

How do you think when thinking deteriorates?

How do you think through how to think when thinking deteriorates?

How do you think through how to think when thinking deteriorates while thinking is deteriorating?

How to write about how to think when thinking deteriorates?

How to write about how to think when thinking deteriorates while thinking is deteriorating?

My circumstances naturally lend themselves to the idea of founding a collective. I have an urgent need to strengthen the three-of-us. I have an urgent need to have an army of my own, to protect the three-of-us from all pollution. Given that one day the disease will limit the means and faculties I currently enjoy, I want to put in place safeguards now, so that these limitations will be balanced out by other intelligences that can continue to provide adequate nourishment for my soul, despite of and, indeed, by way of these same limitations. Such safeguards are not meant to guard us from madness, but rather to keep madness safe in its intrinsic state, to encourage its expression, so that it might be released and inform the world with its fragile teachings. Today, I can be this safeguard for others but one day I will surely need others to take my place for me.

This project means I must consider myself to be Huntingtonian. However all I can say at this stage, given where my thinking is currently up to, is that I do not yet know if I am Huntingtonian. Not because I am yet to display any symptoms of the disease, but because it all depends on how the collective tackles this sprawling entity, that constellation called Huntington's. Unlike many illnesses, especially mental ones, the identification of a gene specific to Huntington's

disease (IT15 on the 4<sup>th</sup> chromosome) should close off the question: “am I Huntingtonian or not?”. There is no doubt that my own gene bears Huntington’s mark: my CAG repetitions exceed normal levels. I’m at 44 on this scale-that-does-not-lie – over 36 and you’ve got Huntington’s. My mother has 42, like her father. My elder sister has 17. The existence of such a “reliable witness” – abnormal CAG repetitions – makes this question obsolete when in fact it is open, open *and* fascinating for a majority of diseases, for which no reliable genetic markers have yet been found.

Schizophrenia is a good example. One of the collectives concerned by this disease believes in not calling itself a gathering of schizophrenics because, in light of its members’ own experiences, it feels that the term “schizophrenic” is less pertinent than “hearer of voices”.<sup>9</sup> The members of this collective hear voices; it’s complicated, it’s uncomfortable and at times painful, it may not be normal, but that doesn’t make them schizophrenics (particularly because “schizophrenic” immediately seems to mean one thing only: the imperative to take neuroleptics for the rest of your life – which is something some choose not to do, in any case not *at all costs*). They prefer, and I agree with them on this, to call themselves Hearers of voices because not only does this mean they have an ability that other “normals” do not, but also that the goal of their treatment be not to eradicate this additional ability but to live a better life with it. Their question is not “how do I treat my schizophrenia?” but “how do I live a better life with my voice-hearing ability?”

Thanks to the Hearers of voices, I can rephrase my question. The problem is not: to be or not to be Huntingtonian, but rather: what do I gain from defining myself as Huntingtonian? It’s about transforming a tragic question into a Jamesian question: what is the better wager? What is the wager that conjures the most vitality? What do I win, and what do I lose by suggesting I am Huntingtonian? The stance taken by certain people with autism is helpful for thinking this question through. Unlike the Hearers of voices, some people with autism not only accept but uphold their autistic status, *yet only insofar as* adopting such a position means acknowledging the singularity of their world, a world which is theirs and resolutely not ours: Autistic culture. They therefore do not ground themselves in a hierarchy that runs from normal to pathological, but rather in the simple acknowledgment of

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<sup>9</sup> Hearing Voices Network. <http://www.hearing-voices.org/>

difference. In other words, these autistic individuals rally behind the medical syndrome known as Autism, yet they do so in order to arrive somewhere far beyond obedient adherence to its medical definition (handicap, deficiency, other-than-normal). This Autistic culture movement leads, for instance, to the discovery of another culture, diametrically opposed and foreign to theirs, Neurotypic culture, which is to say normal people's culture, which they cheerfully conceive of as some kind of incurable pathology.<sup>10</sup> The fact such groups exist is an extraordinary boon to me. If I'm possessed of any confidence in my efforts, it's because their audacity is infectious.

(I won't hide that founding a collective is somewhat entangled with my own personal writing project, as I also need the collective to continue this work. The project, titled *Tahitidouche*,<sup>11</sup> is a literary and existential project. It's the starting point for the search for my own language, for my own sense of reason and of madness. Writing is the most precious and reliable means at my disposal for hosting the creations to which my Huntingtonian life is now bound. Because writing is both how I remember and how I create. I am unable to create anything outside of writing and I am unable of remembering anything that is not written down. If Huntington's disease is a world waiting to be discovered, she – Huntington's is indeed female, as in the French language the words "Land" and "Disease" are feminine – needs her own language, her own mythology, her own founding texts. I need the collective to inform the mode of writing which can speak, describe and bring Huntington's into existence, thanks to the shared experiences it will provoke and thanks to the Huntingtonian us-jectivity (*nousjectivité*) it will reveal. I have no doubt whatsoever that the primary material of this us-jectivity will be text.)

Dingdong's challenge is to establish a system of knowledge production that articulates the collection of individual accounts with the development of new pragmatic proposals, with a view to helping its users\* (*usagers*) – carriers, patients, kin, carers – to live with Huntington's honorably. Original forms of collaboration between users, researchers (medicine, philosophy, sociology, history) and artists (fine artists, writers, videographers, choreographers...) are needed for an endeavor such as this: probing this disease as

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<sup>10</sup> Cf. "Institute for the Study of the Neurologically Typical", <http://isnt.autistics.org/dsn.html>.

<sup>11</sup> Some of this project's ideas will be developed within the foam laboratory and research unit in the Institute of coproduced knowledge on Huntington's disease.

unchartered territory and discovering narrative forms capable of relating this adventure as it unfolds.

In this sense, there's no one goal to achieve, no pre-determined production for instance, rather a kind of expedition to carry out whose worth's unknown although his height be taken. By ridding ourselves of a specific goal, we're delivered from that same panic felt by Huntington's carriers who have undergone the predictive test and who are continually shepherded towards the disease as the sole apex, endpoint, and inescapable onward destination in life. Yet everything changes if we refuse to be blithely captivated by this eerie attraction to the somewhat distant and dangerous planet pointed out to us by the medical profession. Far off, and far removed from our current condition, held aloft as some kind of solar system at the heart of which lays a fatal star, the sun of death. Everything changes if we choose, instead, to look at our feet, to look all around us, just behind us, or just in front us: if we begin to observe the ways in which we're already in contact with this thing. Everything changes if we consider what is happening right now, we're *already* making contact, in other words: it's already an event.

This planetary metaphor is no coincidence.<sup>12</sup> With considerable nuance, Lars Von Trier's film *Melancholia* relates the different possible ways of facing, and handling a foretold catastrophe. In brief: a planet called Melancholia is about to crash into Earth, and we witness a family's last days – a couple, their sister in law, and young son. The husband character played by Kiefer Sutherland believes tooth and nails in the official/scientific assessment that the planet will just brush past Earth before continuing its onwards trajectory. He is so deeply convinced that when he realizes the scientists were wrong/lie (we never really find out, and for once this isn't the point), he kills himself by swallowing the vial of poison his less trusting wife procured. Her character, Claire, played by Charlotte Gainsbourg, is, on the other hand, constantly afraid: we see her, now paralyzed with fear, now gesticulating wildly, possessed with this terror and unable to do anything other than submit to it, until the very end when she gives in and entrusts herself, body and soul, to her sister Justine, played by Kirsten Dunst. Justine (whose impossible "human" matrimony we followed in the first half of the film), is the only person who seems

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<sup>12</sup> I follow, on tippy-toes, in the footsteps of Emilie Hache, here, who in her book *Ce à quoi nous tenons* deploys Lars Von Trier's *Dogville* to literally make the reader *experience* the moral positions of a societal controversy.

able to experience the planet's encounter. She shares this ability of not shying away from reality with the property's horses who make their own journey, as if to say: the ways that lead us to this encounter are varied and infinite, because they reveal our very inner natures.

*Melancholia* is as much the story of this encounter as it is of the disease, its necessary prelude: a strange affliction that befalls Justine, a nameless sickness, or rather a sickness that does not so much bear the name of the approaching planet, but a sickness that *is* itself the approaching planet. In other words: Justine is not melancholic; Melancholia has taken Justine. Under such circumstances, Justine suffers from not yet having encountered what she already belongs to. Like a fish out of water, Justine is sick from having to exist outside her natural environment, and her condition worsens until she encounters that which, at last, makes her become who she really is. This encounter gives rise to an amazing scene in which, bathing naked in its glow, Justine makes love with the planet. From this moment on, Justine regains her appetite and her strength – she is cured.

I believe you can compare the existential dissonance that afflicts Justine with the impossible encounter experienced by carriers of Huntington's disease – insofar as current medical knowledge sets the conditions for such an encounter, in any case.

It's worth remarking that in this film "official" science tries to be reassuring and constantly intones that nothing bad is going to happen, unlike what happens with Huntington's disease. Yet, indeed, when it comes to the encounter itself the net effect is the same: "don't worry, nothing's happening" and "red alert, disaster imminent!" conjure a paralyzing fear, confronted with something for which no answers can be found but of which one thing is certain, it's really happening. Dingdong is an encyclopedic endeavor whose object is not Huntington's disease but the encounter with a neurodegenerative genetic disease understood as a mysterious planet that has already taken some of us. The researchers involved in this collective – whether they're carriers, patients, doctors, philosophers, sociologists, artists, writers – are committed to using their know-how in order to put to the test modes of understanding, with pride, an experience whose users light the way, and which could one day affect us all: living with a genetically foretold disease.

# ding ding dong

Institute for the Co-production of Knowledge about Huntington's Disease



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For any comment, please write to us: [contact@dingdingdong.org](mailto:contact@dingdingdong.org)